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Recovery as a process: Exploring definitions of recovery in the context of eating-disorder-related social media forums

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Abstract

Objective: Online forums related to eating disorders (EDs) represent sources of support for recovery, and comments on these platforms might therefore highlight aspects of recovery that have been previously neglected in research. *Reddit*, an online discussion platform, hosts several ED-related forums. Due to the unique benefits of examining ED-related social media comments, we aimed to use a qualitative approach to conduct an exploratory study to examine users' conceptualizations of recovery from an ED. **Method:** We extracted public comments mentioning recovery that were posted on three ED-related online forums on *Reddit* between March 2017 and August 2017. We thematically analyzed the data corpus using an inductive approach to examine how recovery is defined in the context of ED-related online communities. **Results:** Two superordinate themes ('Recovery as a Process,' 'Psychosocial Factors') and three subordinate themes emerged (within the 'Psychosocial Factors' theme: cognitive/affective, behavioral/physical, social). **Discussion:** The data support a definition of recovery that includes positive aspects of well-being and quality of life. Furthermore, the data highlight that recovery is experienced as an ongoing process that is unique to each individual.

Keywords: Eating disorder; recovery; social media; *Reddit*; qualitative

Recovery as a Process: Exploring Definitions of Recovery in the Context of Eating-Disorder-Related Social Media Forums

Eating disorder (ED) recovery and remission estimates range between 25-84% (Keel & Brown, 2010). The lack of an agreed definition of recovery may partly explain the discrepancy in recovery estimates and is problematic for the field. Recent efforts to operationalize ED recovery have been made (Bardone-Cone, Hunt, & Watson, 2018), yet definitions of recovery still vary among treatment providers, researchers, and patients.

It is crucial to use a standardized definition of recovery to facilitate communication and comparison of outcomes among providers. However, such a definition should also accurately capture the lived experiences of persons with EDs to ensure our models of understanding reflect patients' experiences and meaning of their illness. Thorough examination of persons' qualitative experiences of ED recovery may provide valuable insight into facets of ED recovery that are missed by routine outcomes assessment. Findings from previous studies exploring patients' perspectives have suggested that recovery goes beyond conventional treatment factors, thus highlighting the disconnection between patient and professional recovery goals in treatment (e.g., Duncan, Sebar & Lee, 2015).

For some, social-media platforms represent sources of support for ED recovery (e.g., Aardoom et al., 2014), and comments on such platforms may therefore highlight aspects of recovery that have not been included in previous research. Social-media platforms are beginning to be used to further examine the concept of recovery by those in various stages of change. For example, Keski-Rahkonen and Tozzi (2005) conducted analyses of a Finnish-language ED-related forum and found that participants' concept of recovery changed in tandem with their stage of change. As such comments are unsolicited, they are not influenced by potential researcher biases (e.g., demand characteristics) thus providing an advantage to common researcher-directed qualitative techniques such as interviews and focus groups.

Reddit, one such social-media platform, hosts several ED-related forums (e.g., “subreddits”) that have been the focus of several studies (e.g., Moessner et al., 2018). Given the unique benefits of examining ED-related social-media comments, we aimed to use a qualitative approach to conduct an exploratory study to examine users’ conceptualizations of ED recovery.

Method

Corpus Selection and Data Extraction

We extracted the data corpus from a freely available archive of public comments made on *Reddit* (Complete Public Reddit Comments Corpus, 2018), and limited the data to a six-month period (March 2017 to August 2017). In line with a similar study that analyzed ED subreddits more generally (McCaig et al., 2019), we focused our analyses on a group of three recovery-focused EDR subreddits: *r/eating_disorders*, *r/EatingDisorders*, and *r/fuckeatingdisorders*. Using an existing list of five recovery terms (‘recovery’, ‘recover’, ‘recovers’, ‘recovered’, ‘recovering’), we extracted all comments posted on the three subreddits that included at least one recovery term. This study was deemed exempt from requiring ethical approval by the King’s College London ethical board, and we provided the Python code (Python Software Foundation, 2017) written for data extraction as Supplementary Material.

Data Analysis

We analyzed the data corpus using inductive thematic analysis at a semantic level (Braun & Clarke, 2006). U.F. and T.J. independently conducted a thematic analysis on the data corpus and then compared analyses to reach a consensus on the thematic structure. B.B. acted as a “critical friend” (Smith & Sparkes, 2006) to encourage reflexivity in the thematic structure. We consulted Braun and Clarke’s six-step guide (2006) throughout the analyses and used NVivo 12 software to complete the analyses. Instead of including exact quotations

to support our findings, we paraphrased quotations to prevent identification of commenters through internet searches (cf. Williams et al., 2018).

Results

User Characteristics

In total, 294 commenters generated the data. Commenters self-defined their ED, with self-reported diagnoses of anorexia nervosa, bulimia nervosa, binge-eating disorder, and sub-clinical or non-diagnosed experiences included within the data. Period of recovery was tracked during analysis, and the majority of users self-reported they were ‘in recovery,’ while a smaller sample self-reported they were ‘recovered’ or actively not recovered or engaging in self-defined recovery efforts.

Data Corpus Characteristics

Overall, 2,848 comments were posted in the three subreddits between March 2017 and August 2017; 505 (18%) of the comments contained at least one recovery term and comprised the data corpus for the present study. Each commenter contributed a mean of two comments ($SD = 2$; range = 1-22). Each comment contained a mean of 202 words ($SD = 202$; range = 14-1,996).

Themes

Two superordinate themes (‘Recovery as a Process,’ ‘Psychosocial Factors’) and three subordinate themes (“sub-themes” within the ‘Psychosocial Factors’ theme: cognitive/affective, behavioral/physical, social) were identified. The themes are described in

Table 1.

[Include Table 1 here.]

1 **Recovery as a process.** A central theme was the conceptualization of recovery as a
2 process. The majority of individuals described themselves as ‘in recovery,’ while a small
3 number identified as ‘recovered.’ Irrespective of how individuals identified as themselves
4 regarding recovery, commenters used a range of terms including ‘*journey*’ and ‘*path*’ to
5 describe their developing process of recovery that encapsulated an array of stages, rather than
6 describing recovery as an end process (e.g., recovery was about more than merely
7 gaining/losing weight or abstaining from ED behaviors). Central to this theme for many
8 commenters was that the recovery process was unique to them, their experiences, and their
9 recovery goals, meaning there is no “one-size fits all” definition of recovery due to individual
10 differences in each person’s recovery journey.

11 In addition, commenters described stages of recovery which can be loosely
12 represented by the Transtheoretical Model (Prochaska & DiClemente, 1983), which has been
13 used previously as a theoretical framework for ED recovery (Keski-Rahkonen & Tozzi, 2005;
14 Bardone-Cone, 2012). Contemplation was at the core of the ED-related forum discussions
15 with recovery being conceptualized as a ‘*choice*’ that resulted from an event or ‘*turning*
16 *point*’ to the realization that the “*benefits*” of the ED no longer outweighed the negative
17 physical, social, and/or mental outcomes. While the desire to ‘*choose life*’ over the ED was
18 core to creating a need to change, there was a definite need for preparation and determination
19 within the action stages of this change as commenters reflected that the reality of recovery
20 was a ‘*long, exhausting and difficult path.*’

21 Several commenters noted their need to choose recovery every morning. Furthermore,
22 commenters reflected that recovery was not merely an end-goal but instead was a ‘*constant*
23 *process*’ that differs for each individual. Relapse during this process was an important theme,
24 as many commenters noted that recovery is ‘*not a linear process*’ as it will have “ups and

downs,” as well as relapse, which was widely recognized as a normal and oftentimes necessary part of the recovery process.

Psychosocial factors. Three psychosocial factors comprised the second sub-theme, in which commenters described a range of positive aspects to recovery. Under the sub-theme of cognitive and affective factors, many commenters stated that recovery equated to an experience of ‘*freedom*’ from the negative effects of the ED, such as feelings of guilt, the compulsion to engage in rituals, and preoccupation with food, calories, and weight. Commenters described positive attributes of emotional well-being, such as ‘*happiness*,’ a sense of ‘*authenticity*,’ and connection to others, but also mentioned the ability to connect to painful emotions. Commenters spoke of coping differently in order to ‘*break the cycle*’ and create ‘*healthy thought processes*.’ Relatedly, many emphasized behavioral and physical factors, with a change towards regular eating being an often-cited part of the recovery process. Moreover, recovery was said to entail a state of positive physical health in which one’s ‘*body is able to function properly*.’ Finally, social factors played an important role in descriptions of both the process and outcome of recovery. For instance, interactions with close others were reported by some as critical in providing the initial motivation to recover, and also in providing social support during recovery. Commenters also described increased social connectedness as a positive attribute of recovery, whereby the ‘*world opens up*’ and they may experience ‘*closeness to others*.’

Discussion

Our findings support and expand upon existing research on consumer perspectives on ED recovery. In keeping with De Vos et al.’s (2017) meta-synthesis of qualitative studies, commenters in our study highlighted the importance of including positive psychosocial indicators of well-being in recovery definitions. Our data lend support to the critique that the behavioral or psychological symptoms often at the focus of contemporary treatment models

do not match the complexity of the recovery process. Furthermore, existing definitions of recovery have largely focused on behavioral, psychological, and physical markers of recovery, usually in a categorical way (e.g., Bardone-Cone et al., 2010). Our findings are supportive of an emerging consensus on the importance of a broader conceptualization of recovery, beyond weight status and physical symptoms. This study replicates themes identified in interview-based qualitative studies of recovered individuals, thereby extending the validity of such findings, given the difference in sampling method, which includes unsolicited comments from social-media users who typically reported still being in the process of recovery. Furthermore, these definitions of recovery were consistent across a range of ED presentations, suggesting that meaningful recovery definitions can be developed that transcend specific diagnostic categories.

The present findings suggest that recovery definitions can only represent consensus statements within the field (e.g., Wade & Lock, 2019), and are unable to represent person-specific meanings of ED recovery. This is because people with lived experience of EDs frequently emphasize the unique, individual nature of the recovery process, as in our findings, and also because the meaning of recovery itself appears to differ when self-assessed by persons with lived experience of EDs, as compared to research-based criteria (Slof-Op't Landt, Dingemans, de la Torre Y Rivas, & van Furth, 2019). If the meaning of ED recovery varies between individuals and also across time (Keski-Rakkonen & Tozzi, 2005), this has important implications for both practice and research. In treatment, the use of personalized goals would help to ensure that therapy is congruent with person-specific meanings of recovery. For research, further development and validation of patient-centered outcome measures would constitute one means to advance the agenda of personalized, recovery-focused care (Simpson et al., 2016).

1 The findings also suggest that treatment services which employ a process-focused,
2 rather than categorical, theory of recovery may be more congruent with the lived experiences
3 of persons with EDs. A dimensional, process-focused approach to the definition and
4 prognosis of recovery aligns with recent research that found dimensional modelling of ED
5 pathology to better predict ED course and outcome over time (Forbush et al., 2018). Given
6 the long-term nature of ED recovery and the constraints of current access to treatment (e.g.,
7 insurance covering only a limited number of sessions), it may be optimal to have professional
8 support built into treatment frameworks longitudinally, with definition of “critical need” for
9 services as the onset of relapse before the ED is more severe and potentially harder to treat.
10 Supplementary access to care and ongoing support networks – such as moderated online
11 forums – may be helpful between service utilization.

12 **Limitations**

13 Our study must be considered in light of its limitations. Our data-extraction method
14 may have missed other comments that discussed recovery using a synonymous term (e.g.,
15 ‘healed’). However, our aim was to focus on the definition of the general term ‘recovery’ on
16 ED-related forum discussions and we reached saturation of themes. Furthermore, because of
17 the nature of the data corpus and because not all users mentioned a specific diagnosis, we
18 were unable to examine themes of recovery in specific ED diagnostic categories.

19 **Conclusion and Future Directions**

20 In conclusion, our findings suggest recovery is an ongoing and multifaceted process.
21 Longitudinal follow-up studies with qualitative research built into the design are warranted to
22 understand predictors of long-term success and relapse and to understand empirically how
23 recovery fluctuates over time. Interpretative phenomenological analyses to explore lived
24 experiences of the recovery process represent iterative next-steps toward understanding
25 mechanisms that contribute to recovery maintenance and relapse. We recommend that

- 1 persons with lived experience of EDs be key collaborators in future research efforts,
- 2 including the development of psychometrically robust measures of recovery that are
- 3 consistent with themes identified in this study.

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1 Table 1

2 *Eating-disorder subreddit themes.*

Theme	Description	Sub-themes	Examples
¹ Process	<ul style="list-style-type: none"> - Recovery is a non-linear process, including several steps, and is unique to the individual. - These steps can be positive/forwards (e.g., positive choices, realizations), or negative/backwards (e.g., relapse). There is not always a definitive end to the recovery process. 	<ul style="list-style-type: none"> - Recovery is a process - Everyone's path to recovery is different - Turning point (main) - 'Choose life' - Recovery is not linear; relapse is normal - Tired of ED as motivator 	<ul style="list-style-type: none"> - 'struggle' - 'long ass thing' - 'exhausting' - 'fucking sucks' - 'long' - 'difficult' - 'two years of switchbacks' - 'it's a path'
² Cognitive and affective factors	<ul style="list-style-type: none"> - Cognitive and affective factors that comprise, influence, and result from recovery. 	<ul style="list-style-type: none"> - Commitment - Challenging the ED (e.g., 'feelings aren't facts') - Reconnecting with one's body - Connecting to painful emotions - Coping differently - Identity - Improved emotional well-being - Recovery = freedom 	<ul style="list-style-type: none"> - 'forgiveness' - 'wanting to change' - 'desire' - 'commitment' - 'have to want it' - 'choice'
² Behavioral and physical factors	<ul style="list-style-type: none"> - Behavioral and physical factors that comprise, influence, and result from recovery. 	<ul style="list-style-type: none"> - Challenging the ED (e.g., breaking habits) - Reconnecting with one's body - Better physical health - Normalizing diet 	<ul style="list-style-type: none"> - 'focus on what my body can do' - 'focus on body function instead of weight'
² Social factors	<ul style="list-style-type: none"> - Social factors that comprise, influence, and result from recovery. 	<ul style="list-style-type: none"> - Social connectedness - Social connection 	<ul style="list-style-type: none"> - 'admitting to loved ones how bad it was' - 'best thing is the closeness I feel with other people'

3 *Note:* ED = eating disorder; The two superordinate themes are denoted by superscript: ¹Recovery as a Process, and ²Psychosocial Factors;

4 quotations have been paraphrased to protect the identity of individual commenters.